

WRITTEN STATEMENT OF KATE ADAMSON

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Committee on Government Reform

Subcommittee on Criminal Justice, Drug Policy and Human Resources

“Federal Health Programs and Those Who Cannot Care for Themselves: What Are Their Rights, and Our Responsibilities?”

My name is Kate Adamson. I'm a hemiplegic; the left side of my body is paralyzed. I can talk to you about the issues of care for incapacitated adults as very few people can. I know what life sustaining measures are like from first hand experience. I know what it is like to be hooked up to respirators, to be fed by a feeding tube. I even know what it is like to have your feeding tube turned off for eight days. You will hear in these hearings from many people who have opinions, but in my case you will hear not only my opinion but you will hear about my first hand experience.

10 years ago I had some very firm ideas about the kind of medical care I would want if I ever suffered a catastrophic injury or illness. I knew in my mind that I never wanted to be a burden to my family. I knew that I would be brave and that I could face death as a modern person. I wanted no heroics when my time came. Of course my idea of when my time would come was pushed off to somewhere in the mid 21 first century, when at 96, I would have my 36 great grand children at my side.

I imagine that the honorable members of this committee all have very strong ideas themselves about what they would want to do. Well here - the first thing I can tell you about my personal experience: forget your notions. My time came a little bit short of 96; at 33 I faced death. I was as fit as a person could be and as healthy as a person could ever be. So, if anyone thinks it can't happen to them, they are surely wrong. At 33 I was a young mother with everything to live for and the next moment a totally helpless person who could do nothing for herself. I was now a woman hooked up to every machine imaginable with four IVs running into my arms and a tube placed into my stomach providing me the only nourishment I was able to receive. I was a woman who,

outwardly, appeared to have suffered such a catastrophic injury that surely she would die soon. I was a woman who was fully conscious, alert, awake, aware and in extreme pain with no capability of expressing what I thought.

As I laid there in my room I heard the doctors talk about my impending death and their plans not to treat me. I can assure you at that moment of abject fear and despair my idea of what was the right thing to do for an incapacitated person had drastically changed from my early uneducated beliefs. You may think you know what you will do when you are in a fox hole, but you don't. If you have not been there, you should not presume to know how that person really feels.

Let me tell you what it is like to be aware of what is going on but have to rely upon others to speak for you. When they inserted a feeding tube into my stomach, thinking I could not feel, in fact, I could feel everything but I could do nothing. I FELT EVERYTHING THEY WERE DOING. I felt every cut, every second. I had no way to communicate. I was totally locked into my body, unable to speak, unable to move any muscle in my body. At one point my tube was turned off for eight days and I suffered all the pains and agonies of starvation. I was in excruciating pain, in silence. I was on the inside screaming out; I DO NOT WANT TO DIE. DON'T STARVE ME. I WANT TO LIVE, FEED ME SOMETHING.

If I had not had a loving determined husband to speak for me, I would be dead now. I think if I had not known I could count on my husband Steven to do everything he could to save me, I might have given up at the beginning of this episode and died. Of course, knowing what I know now, I realize that my death would have been agonizingly slow and painful.

When I waged my fight to get treatment, the way life was viewed in this county was a potent weapon in my husband's fight to save me. In 1995 you just didn't let people die without a fight. You just didn't starve people to death. Today we do. Today courts back up foolishness and selfish disregard for human life with court orders that terminate life

solely because some judge determines that that life is not worth living. Just because someone is a judge, they are given the unbridled power and authority to inject their own, perhaps misguided, opinions regarding the so-called value of a human life.

Judges are willing to end lives based upon the shakiest of pure hearsay evidence, often evidence presented by guardians who may no longer have their wards best interests at heart or, as Judge Greer found with Michael Schiavo, guardians who have a conflict of interest. A husband who may no longer love his wife, a spouse who has moved on and formed another primary relationship are allowed to provide hearsay evidence in support of their conflicted interest, evidence that has the power to snuff out human life. They are supported by people like Dr. Ronald Cranford, who is touted as an expert in this field, who has expressed the opinion that it is near barbaric to care for some people who are disabled just because he thinks there is no value to living life with a significant disability.

I doubt I would have been asked to testify today if not for what happened to Terri Schiavo. I think the Schiavo case is a awful blot on this country that will stain us for years and years to come. I believe that Michael Schiavo lied about what Terri said. I might be wrong about that or I maybe right. It is so hard to tell who was telling the truth about what Terri wanted. What is for sure though is just how easy it is to put whatever words you want into the mouths of those who cannot speak for themselves. We should learn from the Schiavo case and never again allow any court to trust the kind of flimsy evidence that was used to put Terri Schiavo to death. We should never again allow such a decision to be made by one single judge, whose judgment may be right or may be wrong. We should never again allow courts to ignore new scientific capabilities or evidence where a human life is involved.

Even if Terri said the things Michael said she did, it should not have been enough to warrant taking her life. Terri was 22 when she was supposed to have stated her dying wishes; she had no way of really knowing what the true import of her words could be. She had no idea at that age just how precious life was. I am not sure anyone can tell

what a gift life is until they actually face losing it. One only need look at the number of people who have been exonerated of involvement in a crime since the ability to analyze DNA was established a few years ago. Many of those people actually were released from death row. Terri Schiavo should have been given the chance to gain her release from the death row imposed upon her by her estranged husband, a misguided judge and lawyers and so-called experts who are, in fact, proponents of euthanasia.

If you asked me prior to my stroke if I wanted to live in my present condition if I wanted to go through what I went through just to live, I think that I likely would have said no. If you ask me today if I want to live as I am or if I think it was worth going through all I went through to live, the answer would be a resounding YES!

I am disabled and I accept it. As a disabled person I can tell you something special about how precious life is. My life is as important as any life. My children love me as much as any children love their parents; my husband loves me as much as when I had two good arms and two good legs. I have an active life; I work, I spend money and I vote. Should I have less right to medical care than the members of this committee? Should I or any other disabled person be made to feel like a second class citizen? That is exactly how I feel today.

Why wouldn't I feel second class? Judges in this year 2005, both Federal and State, have clearly said to people like me that we don't count. Judges said to my family that I was not worth as much as an able bodied person. You think I am wrong? Then tell me one case when this Congress or the courts of this land have ever allowed an able bodied man or women to starve to death. Please explain to my children how starving Terri Schiavo was any different than taking a life in the gas chamber, aside from the fact that the gas chamber is less excruciatingly painful, and does not take as long to kill someone.

I know you won't like me saying this, but they did start with the disabled in Nazi Germany. If you start allowing judges who are accountable to no one to make decisions

about what lives are worth protecting and what lives are not worth protecting you are farther along to acting like Nazi Germany than you may realize. First kill the conscience of the people and then you can kill the people.

Terri's case went so badly array because antiquated civil guardianship law was applied to a life or death question. No person should ever be put to death in this country again without providing that person with the same rights you afford to mass murderers.

Michael Schiavo, having won 1.3 million dollars in a malpractice case, from a court he asked to give him the power to care for his wife for the next 50 years, had all the money he needed to hire the experts he needed to "prove" his wife was nothing more than a carrot. They once thought I was carrot too and I can tell you that you can always find so-called experts to say anything. Every member of this committee who is an attorney knows just how right I am about this.

Scott Petersen at the peoples cost got all the experts he needed to defend his life. Terri Schiavo a poor innocent woman got not one penny to help her defend her life. Michael was a selfish misguided man, but he did not take Terri's life, the courts of this country took Terri's life. The order directing the removal of Terri's tube was signed by a judge, not by Michael Schiavo. WE THE PEOPLE took Terri's life. The blood of it is on all our hands. Yours and mine.

If you are looking to make things better in the future, not merely to mourn for Terri Schiavo, then there are some things I believe that you can do that will help. Here comes my opinion.

Never again allow judges the sole discretion to make these kinds of decisions. The courts are no more up to playing God than the legislature or executive is; but if you, our representatives in Congress, did the kind of things the courts have done in the Schiavo case, at least we, the people, could vote you out of office. In many cases no one can remove a judge from office even though that judge acts with blatant bias, favoritism or

simply an unreasonable insistence upon not ever admitting the possibility of having made a mistake. With such power, there must at least be some means whereby decisions of judges, which may be wrong or improper, can be corrected. That would require that appellate courts establish different tests to apply to the review of such decisions. One of the significant hallmarks of our judicial system was the right to a trial by a jury yet we are so cavalier about denying that for the sake of expedience. We are so loathe to overturn the decision of a trial judge, again, for the sake of expedience. Expedience in the courts should ALWAYS take a back seat to fairness and justice.

I am saying that this Congress needs to take back its rightful role as the final authority on the proper role of the judiciary. Proper checks and balances among the three branches of government do not dictate that we must have a completely unfettered judiciary. The role of Congress should, properly, be to make sure that courts dispense not only "justice" but that the justice meted out by the courts is fair.

All the power government has in this country is on loan from its people. That is what makes America great. If we forget where we came from and who we are then this noble experiment in government is over.

I have lost my confidence in judges alone to make these kinds of life and death decisions. I, for one, want my legislators to better control the judges who are given the task of deciding life and death. I want to require a guardian who wants to end a life to prove every element of his or her case, no matter what the condition of that human life, beyond a reasonable doubt. More than a cursory review of that trial court level decision must be available – particularly for those who are unable to speak for themselves, those who are sometimes the weakest among us. I want you to see to it that every person has a right to have a lawyer whose sole job is to fight for and to argue for their life to be preserved, making that mandatory in all such cases and to pay for that lawyer if the person can not afford it. I want to see to it that the lawyer has all the tools he or she would have if they were defending the worst mass murderer. I want you to make sure that, in a hearing on matters like Terri Schiavo's, the so-called playing field is level, that

the presumption, in the absence of express and explicit written documentation to the contrary from the patient, that the presumption ALWAYS favors life. I want you to see to it that monies recovered for the benefit of someone like Terri can never again be put to use to kill her instead of being used for the intended purpose as it was expressed when it was awarded. I want you to see to it that, in a disputed case like Terri Schiavo's, when a spouse abandons the marriage by living with someone else as though married, or by having children outside of that marriage, that they forfeit the right to keep acting like they are still the spouse.